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Dementia knowledge and attitudes of the general public in Northern Ireland: an analysis of national survey data

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ABSTRACT

Background: This paper provides an overview of the findings from the dementia module of the 2010 Northern Ireland Life and Times (NILT) Survey: an annual survey recording public attitudes to major social policy issues. Northern Ireland, in line with many other developed countries, recently released a Dementia Strategy. The opportunity to explore the knowledge and attitudes of the general public to dementia at a national level in Northern Ireland is timely and valuable. This paper reports on an initial exploration of these attitudes, based on bivariate analysis across demographic groups.

Methods: Data were analyzed using SPSS (Version 19). Descriptive and summary statistics were produced. A series of categorical bivariate relationships were tested (chi-square) and tests of association (Cramer's V) were reported. We discuss both knowledge-related findings and attitudinal findings.

Results: We found that the general public in Northern Ireland have a reasonably good level of knowledge about dementia. However, attitudinal measures indicate the stereotyping and infantilization of people with dementia.

Conclusions: This NILT module provides a unique source of data on attitudes to, and knowledge of, dementia. A key strength is that it provides statistically representative data with national level coverage. This information can be used to target public health education policies more effectively and to inform delivery of health and social services. The success of the module leads us to believe that it stands as a blue-print for collecting information on dementia in other social surveys.

Key words: dementia, stigma, Alzheimer's disease, aging, education

Background

Dementia is a national priority for many countries worldwide with national strategies and plans in place in countries such as Australia, France, Norway, England, and Scotland (Department of Health and Ageing, 2006; Norwegian Ministry of Health and Care Services, 2008; Department of Health, 2009; Scottish Government, 2010). Lobbying is underway for strategies in other countries such as Canada (Alzheimer Society of Canada, 2010; Rockwood *et al.*, 2010). Dementia has been recognized as a public health priority in Northern Ireland policy documents since 1995 (Department of Health and Social Services, 1995). In 2010, a public consultation

was undertaken in Northern Ireland as part of the process of developing a Regional Dementia Strategy (Department of Health, Social Services and Public Safety, 2010). This led to the launch of the Regional Strategy in 2011 (Department of Health, Social Services and Public Safety, 2011). This reflects a global demographic change taking place that poses significant challenges for countries worldwide who will need to provide care and support for people with dementia and their families (Harvard School of Public Health and Alzheimer Europe, 2011). The economic costs of dementia are significant (Knapp and Prince, 2007) as are the costs to families (O'Shea, 2007).

This paper reports on the findings from a survey of the general public in Northern Ireland. Surveys attempting to gather views about dementia have tended to be undertaken with specific population groups or in restricted geographic areas. Previous research has explored the views of professionals

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(Cahill *et al.*, 2008; Ayalon *et al.*, 2009) and family carers (Chung, 2000; Zarit *et al.*, 2010), and in more recent years the views of those diagnosed with dementia (Wilkinson, 2002; Innes *et al.*, 2011). However, the views of the general public have been largely under researched, and such studies are often restricted to knowledge or awareness of symptoms (Bond *et al.*, 2005; Arai *et al.*, 2008; Low and Anstey, 2009; Carpenter *et al.*, 2011). Crisp *et al.* (2000) examined stigmatizing attitudes toward dementia as part of a survey examining stigmatizing attitudes toward seven mental illnesses in Britain. A recent five-country telephone survey examining public perceptions and awareness of Alzheimer's disease (Harvard School of Public Health and Alzheimer Europe, 2011) included a question on attitudes.

Given the level of policy interest, the global concern with the costs of providing care, and the growing number of people upon whom dementia impacts, it is timely to examine not just the views of those concerned with dementia due to personal or work commitments, but also the views of the general public who may in future experience dementia within their families and who also face the challenge of paying for, and providing, care. The exploration of attitudes and knowledge of dementia within the 2010 Northern Ireland Life and Times (NILT) Survey reflects national coverage of this major public health concern. Therefore, this paper reports not only on the first data gathered from the general public in Northern Ireland, but also presents one of the first analyses of knowledge and attitudes of the general public conducted worldwide.

Methods

The Northern Ireland Life and Times Survey is a nationally representative social attitudes survey. This annual survey began in 1998 with the aim of monitoring the attitudes and behavior of people in Northern Ireland to a range of social issues. The questionnaire consists of four modules, each focusing on a particular social policy topic. The survey provides a public resource for academic and policy analysis and debate. (For further information, see Devine, 2011.) In 2010, the survey included a module on knowledge of dementia and attitudes to people with dementia, which was funded by the Atlantic Philanthropies.

The questions were designed by the NILT survey team (including author PD) in partnership with a PhD student and supervisor (authors PMcP and AI) and stakeholders within the field of dementia services and carers' organizations. Standardized

tests, such as the Alzheimer's Disease Knowledge Scale were not appropriate for this study, as the inclusion of a 30-item scale would unreasonably increase the burden on the survey respondents. The team devised a short set of questions to test general knowledge of dementia as well as questions testing if a respondent's attitudes toward someone with dementia varied according to length of time since diagnosis. The instruments explored attitudes on participation and interaction of people with dementia within society in general, and also identified which of a set of positive and negative personality characteristics and emotions were ascribed to someone with dementia. Because the data collection module was incorporated into a general attitudes survey, great care was taken to ensure that questions should be understood clearly by survey respondents. In particular, specialist and medical terminologies were avoided. The majority of attitude questions were measured on a standard 5-point Likert scale. The response options for the knowledge questions were either true or false. For all questions, respondents were able to answer that they did not know and a consistently low percentage of respondents selected this option across the module. A pilot survey was carried out with 60 respondents and positive feedback was received on the dementia module. One question was considered ambiguous by respondents and was therefore removed. Note that this paper does not explore responses to all questions within the module.

The NILT surveys adults aged 18 years or more. The 2010 survey had a 58% response rate ($n = 1,204$). In order to estimate non-response bias, a comparison of demographic characteristics of NILT respondents was carried out with those from a large-scale government survey (2009/10 Continuous Household Survey), which did not indicate any concern with the NILT sample (see Devine, 2011). A stratified random sampling strategy was employed to ensure correct geographical coverage. This is standard practice in Northern Ireland social surveys (Devine, 2004). The data are weighted to adjust for differential household sizes. People living in institutions (though not in private households in such institutions) were excluded from the survey. The survey consisted of a main questionnaire that was undertaken using Computer Assisted Personal Interviewing (CAPI) as well as Computer Assisted Self Interviewing (CASI). The data were analyzed using SPSS (Version 19). Descriptive and summary statistics were produced. A series of categorical bivariate relationships were tested (χ^2) and tests of association (Cramer's V) were reported. The datasets and associated documentation can be obtained from www.ark.ac.uk/nilt.

Table 1. Respondent characteristics

		%
<i>Sex</i>	Male	48
	Female	52
<i>Age</i>	18–24	11
	25–34	17
	35–44	19
	45–54	19
	55–64	16
	65–74	12
	75 and over	6
<i>Marital status</i>	Single	24
	Married/civil partner/cohabiting	64
	Divorced/separated	7
	Widowed	5
<i>Educational qualification</i>	Degree or higher	17
	Higher education	15
	A level	15
	GCSE A–C	18
	GCSE D–G	7
<i>Occupation</i>	No qualifications	28
	Non-manual	57
	Manual	43
<i>Know someone with dementia</i>	Yes	45
	No	55
<i>Caring responsibilities</i>	Is a carer	26
	Is not a carer	74
<i>Religious denomination</i>	Catholic	38
	Protestant	49
	No religion	13

Results

Of the 1,204 respondents, 52% were female and 48% male. Age groups ranged from 18–24 years to 75 years and more, and 64% of the respondents were married. Despite considerable immigration throughout the previous decade, ethnic diversity is not a major feature of the population within Northern Ireland: 98% of the NILT respondents classified themselves as “white”, and 5% said that they would consider themselves to be a member of an ethnic minority community. Thus, it is not appropriate to undertake analysis by ethnic group.

Table 1 presents full details of the respondents’ characteristics. Forty-five percent (45%) of the respondents knew someone with dementia. This figure is lower than that recorded in a recent survey across Europe and the USA (Harvard School of Public Health and Alzheimer Europe, 2011). As might be expected, figures were lower among younger age groups: for example, 23% among those aged 18–24 years compared with 56% of those aged 55–64 years. Of those who knew someone with dementia, 56% identified a family member, 21% a friend, and 23% an acquaintance.

Respondents were initially asked to respond “true”, “false”, or don’t know to a series of statements designed to examine knowledge about dementia (Table 2). While most respondents were aware that dementia was a disease of the brain (94%), 54% viewed dementia as a mental illness, and 28% believed that dementia was part of the normal aging process. A high percentage of respondents were aware that there are drug treatments to help with dementia (75%). This is higher than in other parts of Europe where the figures ranged across countries from 27% to 63% (Harvard School of Public Health and Alzheimer Europe, 2011). However 64% of respondents were unaware that diet and exercise may have a preventative effect on the likelihood of developing dementia.

As can be seen in Table 3, a large proportion of those surveyed (83%) responded that there comes a time when all you can do for someone with dementia is to keep them clean, healthy, and safe, and 75% agreed that once they have dementia the person you knew eventually disappears. While a relatively low percentage of people agreed with the idea that life is not worth living for people with really bad dementia (27%), just over half of those surveyed disagreed with this statement (53%).

In terms of care, 73% agreed that people with dementia are like children and should be cared for as you would a child. While 34% of respondents agreed that it is better for people with dementia to be cared for in a residential/nursing home, almost the same percentage (33%) neither agreed nor disagreed, suggesting a recognition of variance in the situations of people living with dementia. On the issue of diagnosis, 37% responded that there was little or no benefit in telling someone that they had dementia.

Themes of independence for people with dementia were also explored (Table 4). The questions were asked first in the context of someone who had just been diagnosed with dementia and then in the context of someone who had been living with dementia for a long time.

For people who had just been diagnosed with dementia, 46% of those surveyed responded that people should not continue to live alone. Sixty-three percent responded that people should not continue to manage their own medication, and 80% said they should probably or definitely not continue to drive. Respondents were also very supportive (64%) of fitting electronic tags so that someone could be located if they wander. When asked about people who have lived with dementia for a long time, 81% of people responded that they should probably or definitely not live alone and 87% responded that they should not continue to manage

Table 2. Respondent's knowledge of dementia

	% Reporting "True"							
	Dementia Is a Disease of the Brain	Dementia Is a Mental Illness	Dementia Is Part of the Normal Process of Aging	Dementia Is Another Term for Alzheimer's	People Who Eat Healthily and Exercise Regularly Are Less Likely to Get Dementia	There Are Drug Treatments that Help with Dementia	There Are Many Different Kinds of Dementia	Dementia Can Be Cured
All	94	54	28	58	29	75	72	6
Sex	*(<i>V</i> = 0.078)	**(<i>V</i> = 0.112)		*(<i>V</i> = 0.073)	***(<i>V</i> = 0.124)			*(<i>V</i> = 0.085)
Male	92	60	29	55	35	75	70	8
Female	96	49	27	61	24	76	73	4
Age	**(<i>V</i> = 0.108)	***(<i>V</i> = 0.143)	***(<i>V</i> = 0.143)	***(<i>V</i> = 0.176)	***(<i>V</i> = 0.161)	***(<i>V</i> = 0.127)	*(<i>V</i> = 0.095)	
18–24	90	74	16	35	16	67	68	6
25–34	95	59	23	52	24	65	78	7
35–44	96	56	23	59	24	75	77	6
45–54	96	47	24	60	32	84	71	4
55–64	94	41	36	60	31	82	69	4
65–74	94	50	42	71	41	79	66	3
75+	87	63	42	74	53	68	65	12
Marital status	*(<i>V</i> = 0.076)	***(<i>V</i> = 0.107)	*(<i>V</i> = 0.081)	***(<i>V</i> = 0.108)		*(<i>V</i> = 0.075)		
Single	93	67	24	51	24	68	67	7
Married/civil partner/ cohabiting	95	50	28	58	32	78	74	5
Separated/divorced	93	52	37	68	24	76	67	4
Widowed	89	54	36	71	32	84	66	8
Occupation		**(<i>V</i> = 0.104)					**(<i>V</i> = 0.104)	**(<i>V</i> = 0.110)
Non-manual	94	51	26	56	30	77	75	3
Manual	94	57	30	59	27	73	66	8
Educational qualification	*(<i>V</i> = 0.094)	*(<i>V</i> = 0.088)	***(<i>V</i> = 0.163)	***(<i>V</i> = 0.165)		**(<i>V</i> = 0.107)	***(<i>V</i> = 0.13)	*(<i>V</i> = 0.092)
Degree	97	48	26	51	30	85	79	4
Higher education	95	51	16	53	25	77	76	4
A level	94	58	23	50	28	73	79	6
GCSE A–C	94	59	22	57	29	70	74	2
GCSE D–G	91	56	30	64	29	82	61	7
No quals	92	55	42	69	33	83	62	9
Know someone with dementia		**(<i>V</i> = 0.092)		**(<i>V</i> = 0.107)		***(<i>V</i> = 0.134)	*(<i>V</i> = 0.087)	*(<i>V</i> = 0.083)
Yes	94	50	28	63	28	82	76	4
No	94	57	28	54	30	70	68	7

Table 2. Continued

	% Reporting "True"						
	Dementia Is a Disease of the Brain	Dementia Is a Mental Illness	Dementia Is Part of the Normal Process of Aging	Dementia Is Another Term for Alzheimer's	People Who Eat Healthily and Exercise Regularly Are Less Likely to Get Dementia	There Are Drug Treatments that Help with Dementia	There Are Many Different Kinds of Dementia
Carer							
Yes	94	54	28	58	30	74	71
No	93	54	28	59	27	80	73
				***($V = 0.097$)			*($V = 0.074$)
Religious denomination							
Catholic	94	53	30	64	27	74	77
Protestant	93	55	27	58	29	76	68
No religion	96	55	24	44	32	79	72

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.
Cramer's V in parentheses.

their own medication. Almost all of those surveyed (93%) responded that they should not continue to drive and 69% of people agreed that someone who had dementia for a long time should probably or definitely have an electronic device fitted.

We undertook a series of bivariate analyses in order to explore attitudes and knowledge across a range of demographic groups, which have proved to be significant among attitudinal research in Northern Ireland (see for example, Lloyd *et al.*, 2004). The key independent variables used in this paper are gender, age, marital status, education, knowledge of someone with dementia, and religion. Given the paucity of public attitude research on this topic, this analysis was exploratory. Gender differences in level of knowledge have not been generally identified. However, Arai and colleagues (2008) found that females had more knowledge about dementia than did males among a study of the Japanese general public, and hypothesized that this may be due to women being more involved in care-giving. The pattern of knowledge among different age groups has been inconsistent, and Arai *et al.* (2008) found a non-linear relationship with age. Carpenter *et al.* (2011) found that greater knowledge about dementia was associated with having family members with dementia.

Gender

Gender was significant across some but not all of the responses to knowledge statements (Table 2) although the associations were weak. Significantly more men than women (35% compared with 24%) agreed that "people who eat healthily and exercise, are less likely to get dementia." Significance was evidenced against only three of the attitude statements (Table 3). A higher proportion of males (86%) compared with females (80%) agreed that there comes a time when all you can do for someone with dementia is to keep them clean, healthy, and safe ($p = 0.01$), and 78% of females compared with 71% of males agreed that "once they have dementia the person you knew eventually disappears." Males were more inclined to support nursing home or residential care (40% compared with 28%). In terms of independence, males were significantly less supportive of people with dementia who had just been diagnosed continuing to live alone. For other scenarios, responses between males and females were similar to each other.

Age

Age was significant when tested against all knowledge statements (Table 2), although the patterns are non-linear and any association was found to be weak. Almost double the percentage

Table 3. Attitudes toward people with dementia and their care

	% Responding 'Strongly Agree' or 'Agree'										
	There Comes a Time When All You Can Do for Someone with Dementia Is Keep Them Clean Healthy and Safe	Other People Take Over Making Decisions for People with Dementia Far Too Much	Once They Have Dementia the Person You Knew Eventually Disappears	As Soon as Someone Is Diagnosed with Dementia, They Are Not Treated Like a Thinking Human Being Any More	For People with Really Bad Dementia Life Not Is Worth Living	People with Dementia Are Like Children and Need to Be Cared for as You Would a Child	People with Dementia Should Be Involved in Activities in the Community	It Is Better for People with Dementia and Their Families if They Are Cared for in a Residential or Nursing Home	There Is Little or No Benefit to Be Gained from Telling Someone They Have Dementia	People Who Have Just Been Diagnosed with Dementia Are Unable to Make Decisions About Their Own Care	There Is No Point in Trying to Talk to People with Dementia as They Won't Be Able to Understand
All	83	48	75	46	27	73	87	34	37	29	14
Sex	*(<i>V</i> = 0.084)		*(<i>V</i> = 0.094)					***(<i>V</i> = 0.131)			
Male	86	46	71	41	26	73	85	40	38	32	15
Female	80	50	78	50	28	74	88	28	36	27	13
Age	***(<i>V</i> = 0.126)		***(<i>V</i> = 0.187)		***(<i>V</i> = 0.117)	***(<i>V</i> = 0.137)	**(<i>V</i> = 0.10)	***(<i>V</i> = 0.139)	***(<i>V</i> = 0.183)	***(<i>V</i> = 0.165)	***(<i>V</i> = 0.149)
18–24	81	45	42	48	9	51	92	35	19	22	9
25–34	78	47	69	43	27	68	91	35	24	24	11
35–44	73	50	76	42	21	67	86	23	28	20	8
45–54	81	46	83	47	31	78	88	25	36	24	12
55–64	89	48	85	50	33	83	82	38	49	31	15
65–74	96	52	85	53	36	83	86	49	56	49	29
75+	91	45	72	37	27	84	71	52	61	53	30
Marital status			***(<i>V</i> = 0.101)						**(<i>V</i> = 0.087)	**(<i>V</i> = 0.082)	**(<i>V</i> = 0.087)
Single	80	45	62	45	20	68	86	36	27	29	16
Married/civil partner/cohabiting	83	90	79	46	27	74	87	33	39	27	12
Separated/divorced	86	50	83	58	35	78	82	34	43	39	17
Widowed	87	44	77	41	38	84	76	44	51	42	29

Table 3. Continued

% Responding 'Strongly Agree' or 'Agree'											
	There Comes a Time When All You Can Do for Someone with Dementia Is Keep Them Clean Healthy and Safe	Other People Take Over Making Decisions for People with Dementia Far Too Much	Once They Have Dementia the Person You Knew Eventually Disappears	As Soon as Someone Is Diagnosed with Dementia, They Are Not Treated Like a Thinking Human Being Any More	For People with Really Bad Dementia Life Not Is Worth Living	People with Dementia Are Like Children and Need to Be Cared for as You Would a Child	People with Dementia Should Be Involved in Activities in the Community	It Is Better for People with Dementia and Their Families if They Are Cared for in a Residential or Nursing Home	There Is Little or No Benefit to Be Gained from Telling Someone They Have Dementia	People Who Have Just Been Diagnosed with Dementia Are Unable to Make Decisions About Their Own Care	There Is No Point in Trying to Talk to People with Dementia as They Won't Be Able to Understand
Occupation	***($V=0.153$)					*($V=0.094$)		***($V=0.173$)	**($V=0.119$)	***($V=0.148$)	***($V=0.137$)
Non manual	79	45	77	44	25	70	87	28	35	24	11
Manual	89	50	76	48	30	78	85	40	41	34	18
Educational qualification	***($V=0.118$)			***($V=0.096$)		***($V=0.133$)	***($V=0.111$)	***($V=0.119$)	***($V=0.159$)	***($V=0.176$)	***($V=0.161$)
Degree	75	43	72	35	21	62	94	32	25	15	8
Higher education	78	44	75	39	24	68	86	26	27	21	7
A level	80	48	66	49	24	66	92	36	31	25	11
GCSE A-C	83	49	77	51	28	74	87	25	34	22	9
GCSE D-G	92	55	85	51	28	79	83	44	56	40	17
No quals	90	50	78	50	33	85	80	43	48	46	27
Know someone with dementia			*($V=0.088$)	*($V=0.08$)	*($V=0.086$)				*($V=0.087$)		*($V=0.083$)
Yes	83	49	78	45	30	75	88	34	41	30	14
No	83	47	72	47	24	71	85	34	34	28	15
Carer						**($V=0.103$)	*($V=0.094$)	**($V=0.108$)			
Yes	82	47	75	46	26	71	85	36	37	29	15
No	84	51	75	45	28	78	90	29	35	28	14
Religious denomination	*($V=0.075$)	*($V=0.075$)	**($V=0.095$)	*($V=0.077$)		**($V=0.091$)	*($V=0.083$)	*($V=0.083$)	***($V=0.1$)	**($V=0.098$)	*($V=0.081$)
Protestant	82	52	73	46	26	76	91	31	37	30	14
Catholic	86	45	79	44	29	76	83	38	40	32	17
No religion	76	49	65	56	24	61	87	27	26	14	6

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.
(Cramer's V in parentheses).

Table 4. Attitudes towards independence

	% REPORTING “DEFINITELY NOT” OR “PROBABLY NOT”							
	JUST DIAGNOSED – DO YOU THINK IN MOST CASES THEY SHOULD				DIAGNOSED A LONG TIME – DO YOU THINK IN MOST CASES THEY SHOULD			
	CONTINUE TO LIVE ALONE	CONTINUE TO MANAGE THEIR OWN MEDICATION	CONTINUE TO DRIVE	HAVE AN ELECTRONIC DEVICE FITTED SO THEY CAN BE LOCATED IF THEY WANDER	CONTINUE TO LIVE ALONE	CONTINUE TO MANAGE THEIR OWN MEDICATION	CONTINUE TO DRIVE	HAVE AN ELECTRONIC DEVICE FITTED SO THEY CAN BE LOCATED IF THEY WANDER
All	46	63	80	15	81	87	93	16
Sex	***(<i>V</i> = 0.122)							
Male	52	64	83	15	82	87	93	15
Female	40	62	77	16	81	87	93	16
Age	***(<i>V</i> = 0.112)	***(<i>V</i> = 0.129)	**(<i>V</i> = 0.108)	***(<i>V</i> = 0.111)	*(<i>V</i> = 0.192)	*(<i>V</i> = 0.091)	*(<i>V</i> = 0.091)	
18–24	51	67	83	14	85	91	92	18
25–34	47	61	80	13	81	85	89	15
35–44	39	49	71	17	73	81	90	13
45–54	43	58	79	18	80	85	92	16
55–64	41	66	86	18	84	89	99	17
65–74	58	79	83	11	86	93	96	16
75+	55	77	89	7	81	91	93	18
Marital status								
Single	50	65	83	14	83	89	94	17
Married/civil partner/cohabiting	44	61	79	16	80	86	82	15
Separated/Divorced	51	63	88	20	81	87	94	20
Widowed	45	62	79	8	79	87	95	10
Educational qualification	***(<i>V</i> = 0.132)	***(<i>V</i> = 0.151)	***(<i>V</i> = 0.111)	***(<i>V</i> = 0.107)	*(<i>V</i> = 0.088)	**(<i>V</i> = 0.100)		
Degree	29	46	68	19	75	82	87	16
Higher education	38	55	78	18	74	80	93	15
A level	48	63	85	15	89	92	93	17
GCSE A–C	46	61	79	13	81	86	93	13
GCSE D–G	53	72	85	13	84	90	95	15
No quals	57	76	86	14	84	91	96	18

Table 4. Continued

	% REPORTING “DEFINITELY NOT” OR “PROBABLY NOT”							
	JUST DIAGNOSED – DO YOU THINK IN MOST CASES THEY SHOULD				DIAGNOSED A LONG TIME – DO YOU THINK IN MOST CASES THEY SHOULD			
	CONTINUE TO LIVE ALONE	CONTINUE TO MANAGE THEIR OWN MEDICATION	CONTINUE TO DRIVE	HAVE AN ELECTRONIC DEVICE FITTED SO THEY CAN BE LOCATED IF THEY WANDER	CONTINUE TO LIVE ALONE	CONTINUE TO MANAGE THEIR OWN MEDICATION	CONTINUE TO DRIVE	HAVE AN ELECTRONIC DEVICE FITTED SO THEY CAN BE LOCATED IF THEY WANDER
Occupation	***(<i>V</i> = 0.149)	**(<i>V</i> = 0.122)	*(<i>V</i> = 0.087)	***(<i>V</i> = 0.149)		*(<i>V</i> = 0.095)		*(<i>V</i> = 0.093)
Non-manual	40	58	78	18	81	86	94	14
Manual	53	68	83	12	82	88	93	16
Know someone with dementia	*(<i>V</i> = 0.085)					*(<i>V</i> = 0.100)	*(<i>V</i> = 0.090)	
Yes	43	62	80	17	83	89	95	17
No	49	63	81	14	79	85	91	15
Carer								***(<i>V</i> = 0.125)
Yes	46	62	80	16	81	87	93	17
No	44	64	82	13	80	88	94	12
Religious denomination			*(<i>V</i> = 0.085)	*(<i>V</i> = 0.078)	*(<i>V</i> = 0.082)			***(<i>V</i> = 0.107)
Catholic	50	65	81	16	84	88	94	19
Protestant	44	63	79	14	80	87	93	13
No religion	42	56	86	15	72	81	90	15

p* < 0.05, *p* < 0.01, ****p* < 0.001.
Cramer's *V* in parentheses.

of respondents aged 65 years or more (71%–74%) regarded dementia as another term for Alzheimer's disease compared with 35% of 18–24 year olds. A similar pattern was found in support of the statement that people who eat healthily and exercise are less likely to get dementia (46% and 16%, respectively). Those in the older age group (75 years or older) were more likely to say that dementia is a mental illness, think that dementia can be cured, and to recognize the preventive effects of healthy diet and exercise. Conversely, this group was less likely to know that there are drug treatments that help with dementia. In response to measures of attitude (Table 3) the most significant differences occur between the youngest age group (18–24 years) and the older age groups, most noticeably the 55–64 years category and the 65 years or above categories. As we noted above, this may reflect the increased likelihood that people in the older age groups will know or have known someone with dementia. In response to the statement “once someone has dementia, the person you knew eventually disappears,” almost twice as many of those aged 45 years and above (81%–86%) agreed compared to 42% of the 18–24 year age group. The vast majority (83%–84%) of those above 55 years agreed that “people with dementia are like children and need to be cared for as you would a child” compared to 51% of 18–24 year olds.

Analysis was undertaken to explore if there were differences within the oldest age group, namely between those aged 65 to 74 years, and those aged 75 years or above. The younger group (65–74 years) was significantly less likely ($p < 0.05$) than the older group (75 years or over) to hold what might be described as paternalistic attitudes. Specifically, the former group was more likely to disagree that there was little or no benefit in telling someone that they had dementia, that people who had been just diagnosed with dementia were unable to make decisions about their own care, and that there was no point in trying to talk to people with dementia as they would not be able to understand. However, the association was relatively weak ($V = 0.21$ through $V = 0.31$).

When it came to attitudes toward independence, the most notable differences were again between the youngest and older age groups. For those just diagnosed, only 7% of 18–24 year olds and 10% of the over 75 year olds felt that people with dementia should continue to live alone. The percentage across other age groups ranged from 16% to 24%. The highest level of support for electronic tagging was in the 65–74 year age group, with little distinction being made between those just diagnosed and those living with dementia for a long time: 80% and 79%, respectively.

Marital status

In terms of knowledge, there were some statistically significant differences according to the marital status of respondents. This is based on a four-category classification (single, married, separated/divorced, and widowed). In particular, respondents who were widowed were the least likely to think that dementia was a disease of the brain (89%, compared with 95% of those who were married). Conversely, respondents who were single were least likely to think that dementia was a normal part of aging (24%, compared with 37% of those who were separated, divorced, or widowed).

There also appeared to be some variation in attitude (Table 3) according to the respondent's marital status. For many statements, respondents who were widowed expressed views which were different to those who were single or married/cohabiting. The attitudes of those who were separated or divorced were often similar to those who were widowed, but this was not the case for all statements. For example, 42% of those who were widowed and 39% of those who were separated or divorced agreed that people just diagnosed with dementia were unable to make decisions about their own care, compared with 27% of those who were married, and 29% of those who were single. In addition, 29% of those who were widowed agreed that there was no point in trying to talk to people with dementia as they would not be able to understand, compared with 12%–17% of the other three marital status groups.

Education

Table 2 shows that in terms of education a statistical significance is recorded against most knowledge statements, but again the association is weak (Cramer's $V < 0.2$). A much higher percentage of those with no qualifications saw dementia as a normal part of aging (42%) compared to those with a degree (26%) and almost twice the percentage of the former thought dementia could be cured compared with those with higher levels of education. A significantly lower proportion of those with GCSE grades D–G and no qualifications knew that there were many different kinds of dementia ($p < 0.001$).

Education proved significant for some but not all measures of attitude (Table 3) and levels of association were generally relatively weak. A general pattern can be seen indicating that the groups with lowest or no qualifications held very different views to those in the highest levels of education. Around one-third (33%) of those with no qualifications supported the statement “for people with really bad dementia life is not worth living,” compared

to 22% of those with a degree or higher ($p < 0.05$). This contrast continues with the groups with lower levels of qualifications indicating a more paternalistic attitude to people with dementia and being much less convinced of the benefits of telling people they have dementia, compared to those respondents with a degree. The proportion of those with no qualifications feeling that there was no point in talking to someone with dementia as they would not understand was three times higher than the proportion of those with higher education who felt this way.

In response to the measures examining attitudes toward the independence of people with dementia (Table 4) education also proved significant. In considering people who had just been diagnosed, approximately twice as many respondents with higher education or a degree supported the idea that they should continue to live alone, manage their own medication, and continue to drive, compared with those with no qualifications. This latter group was most likely to support having an electronic device fitted.

A similar impact can be seen in the context of a person who has been living with dementia for a long time, with respondents with no qualifications being less likely to support this group living alone, managing their own medication or continuing drive, than those with a degree.

Knowing someone with dementia

Knowing someone with dementia had a significant impact on knowledge (Table 2) with 63% compared to 54% describing dementia as another term for Alzheimer's disease. This group was also more aware that there were drug treatments to help and less likely to think that dementia could be cured. In terms of attitudes toward people with dementia (Table 3), a higher percentage of those who knew someone with dementia agreed "once they have dementia, the person you knew eventually disappears" (78% compared with 72%). The greatest difference in these two groups was in their attitude to telling someone their diagnosis with 41% of those who knew someone with dementia feeling there was no benefit compared to 34% of those who did not know someone with dementia. There was also greater support for tagging (Table 4) among those who did not know someone with dementia, both for those just diagnosed (66% compared with 62%) and for those living with dementia for a long time (70% compared with 67%).

Religion

There were some differences in the type and levels of knowledge (Table 2) according to the religion

of the respondents. Sixty-four percent of Catholic respondents said that dementia was another name for Alzheimer's disease, compared with 44% of those with no religion. In addition, while 77% of Catholics thought there were many different types of dementia, a lower proportion (68%) of Protestants thought this. Levels of association were weak.

Some statistically significant differences in attitudes (Table 3) according to religion are evident, although the low values of Cramer's V indicate a weak association. In general, respondents of no religion exhibited less paternalistic attitudes. Thus, while 26% of respondents in this group thought that there was little or no benefit to be gained from telling someone they had dementia, the figure for Catholics and Protestant respondents was much higher (37% and 40%, respectively).

Other demographic variables

While the variables discussed above emerged as most significant, other variables were also considered. NS-SEC classification of social class was recorded for respondents, but given the strong correlation between social class and education, this analysis did not provide us with significant extra information. The impact of the respondent being a carer was also examined but had little significant impact on outcomes. Carers were less supportive of people with dementia being involved in activities in the community, more inclined to agree that people with dementia should be cared for in a residential or nursing home and less supportive of electronic tagging.

Discussion

The results indicate that the general public in Northern Ireland have a reasonable knowledge of dementia. In terms of public health and awareness perhaps one of the most significant findings is that a low percentage of people overall (29%) are aware of the link between diet, exercise, and prevention, with the percentage even lower among younger adults (16% of the 18–24 age group). Over a quarter of those surveyed (28%) viewed dementia as a part of the normal process of aging and this percentage rose according to the age of participants (42% in 65+ age groups). These older age groups are most at risk in terms of dementia and a belief in dementia as a normal part of aging impacts on those seeking support and the potential for early diagnosis. This is an important factor in targeting public awareness and in the delivery of services.

Attitudinal results indicate the existence of deeply stigmatizing attitudes toward people with

dementia. Old stereotypes of the “disappearing person” or the “living shell” (Woods, 1989) continue to exist. The data also suggest a paternalistic attitude toward people with dementia rather than a view of the person with dementia as an equal citizen in society (Kelly and Innes, 2012). People with dementia were viewed as those we should take care of, as we would a child, with the resulting infantilization of the person (Kitwood, 1997). There is evidence of a stereotypical view of the person with dementia with little difference made between a person who has recently been diagnosed and a person who has been living with dementia for a long time. The attitudes held by members of the public appear to be in line with the most degenerative images of dementia.

These bivariate results indicate some differences between different demographic groups and, in general, they reflect some of the findings of Arai *et al.*'s (2008) in relation to gender and age. However, Cramer's V indicates that many of these relationships are weak. The experience of knowing someone with dementia did prove significant in terms of knowledge (Carpenter *et al.*, 2011) but, contrary to what one might expect, it was not a strong indicator of a more positive attitude. However, the limitation of bivariate analysis must be acknowledged. In particular, the association with religion or marital status may be due to the age distribution of particular groups; for example, single people tend to be younger than those who are widowed. Approximately one-third of the Catholic respondents or those with no religion (32%) were aged less than 35 years, compared to 20% of the Protestant respondents, and so the association of attitudes with religion may be an artefact of age. To establish these relationships, multivariate analysis is appropriate. A qualitative exploration of the values and beliefs underlying the attitudes expressed would also be appropriate, and this work is being undertaken in the form of focus groups and interviews as part of the lead author's PhD study.

Conclusions

This NILT module makes an original contribution by providing a unique source of data on knowledge of, and attitudes to, dementia. A key strength is that the survey provides statistically representative data with national level coverage, and as a data resource it is currently unmatched. We anticipate that it will make an important contribution to understanding the general public's knowledge and attitudes toward dementia, given that dementia is such a global, national, and regional concern (Alzheimer's Disease

International, 2011). On its own, the module on dementia knowledge and attitudes will support a range of possible analyses, which are widened because the module is located within a more general social survey, which includes other pertinent social policy issues (such as informal caring). This paper provides an initial exploration of the data at bivariate level; however, further analysis will incorporate comprehensive multivariate statistical analysis. We anticipate that the measures collected suit data reduction techniques and approaches appropriate to analyses of attitudes as well as the testing of interaction effects. We cannot foresee any barriers to the module being replicated in either subsequent NILT surveys or other comparable social attitudes surveys. Repeating the module in a cross-sectional survey context is intuitively appealing as it would allow comparisons, and with subsequent replications it would support the analysis of trends. The success of the module leads us to believe that it stands as a blue-print for collecting information on dementia in other social surveys.

Within a Northern Ireland context, the number of people living with dementia is estimated to treble by 2051, which is the fastest expected rate of increase in the UK (Department of Health, Social Services and Public Safety, 2010). The impact of this will present many issues at personal, family, and societal levels. Educational policies to improve public knowledge of the etiology of dementia are pertinent to public health departments as well as to the delivery of health and social services. Identifying patterns in knowledge across groups could be helpful for practitioners and educators in anticipating knowledge needs (Carpenter *et al.*, 2011). Arai *et al.* (2008) highlight the need to particularly target dissemination of information to groups who traditionally have had less contact with health and social care professionals, such as men and younger people. Identifying the nature of stigmatizing attitudes toward people with dementia is essential if those affected are to be encouraged to seek help and support. The data could also provide valuable information on the extent and demographic make-up of existing stigma so that the plan to address stigma (Department of Health, Social Services and Public Safety, 2011) can be targeted appropriately. The publication of the Dementia Strategy for Northern Ireland at the end of 2011 indicates the level of government concern, although the lack of funding associated with the strategy limits its power.

There is worldwide recognition that dementia will impact on a rapidly increasing proportion of the population and dementia strategies emphasize the need to improve public awareness. The data

gathered through this survey can provide insight on the current knowledge held by the general public and their attitudes toward people with dementia. This information can be used to target public health education policies more effectively and to inform delivery of health and social services.

Conflict of interest

None.

Description of author's roles

Patricia McParland brought the initial idea to ARK, developed the questions, analyzed the data, and wrote the paper. Dr Paula Devine assisted in developing the questions, analyzed the data, and assisted with writing the paper. Professor Anthea Innes assisted with the development of questions, analysis of data, and writing the paper. Professor Vernon Gayle assisted in analysis of data and writing the paper.

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